

Virginia Genetics Advisory Committee
Tuesday, October 4, 2011
10:00 a.m. – 12:00 Noon

Division of Consolidated Laboratory Services
Training Room T-23
600 North 5th Street
Richmond, VA 23219
Telephone (804) 648-4480

MINUTES

VaGAC Members (check = present):

- | | |
|---|---|
| <input checked="" type="checkbox"/> Willie Andrews, DCLS | <input checked="" type="checkbox"/> Sara Long, MOD |
| <input type="checkbox"/> Arti Pandya, VCU (Interim VaGAC Chair) | <input checked="" type="checkbox"/> Jana Monaco, Parent |
| <input type="checkbox"/> Caroline Fuller, DOE | <input type="checkbox"/> Walter Nance, VEHDIP Adv Cmt |
| <input checked="" type="checkbox"/> Eileen Coffman, CHKD | <input type="checkbox"/> William Owen, EVMS/CHKD |
| <input type="checkbox"/> Karen Durst, VDBHDS | <input type="checkbox"/> James Pearson, DCLS |
| <input checked="" type="checkbox"/> Laura Duncan, VCU | <input checked="" type="checkbox"/> Ginny Proud, CHKD |
| <input checked="" type="checkbox"/> Tom Hickey, DCLS | <input type="checkbox"/> Charlie Stevenson, DCLS |
| <input type="checkbox"/> Anil R. Kumar, VCU | <input checked="" type="checkbox"/> Bill Wilson, UVA |

VaGAC and Subcommittee Staff:

- | | |
|---|--|
| <input checked="" type="checkbox"/> Kathleen Moline, Staff - VaGAC & Steering Cmt | <input checked="" type="checkbox"/> Jennifer Macdonald, Staff – NBS Subcmt |
| <input type="checkbox"/> Tiara Green, Staff - BDP Subcmt | <input type="checkbox"/> Rafael Randolph, Staff - VaGAC |
| | <input checked="" type="checkbox"/> Lillie Chandler, Staff |

VaGAC Ad Hoc Members:

- | | |
|---|---|
| <input checked="" type="checkbox"/> Joanne Boise, VDH | <input type="checkbox"/> Ruth Frierson, VDH, VEHDIP Adv Cmt |
| <input type="checkbox"/> Joan Corder-Mabe, VDH | <input checked="" type="checkbox"/> Sidneé Dallas, VDH |

Additional Subcommittee Members / Interested Parties:

- | | |
|---|--|
| <input type="checkbox"/> Rachel Arculin, Parent | <input checked="" type="checkbox"/> Valerie Luther, Partnership, VCU |
| <input type="checkbox"/> Stephen Braddock, UVA | <input type="checkbox"/> Paula Miller, Parent |
| <input type="checkbox"/> Heather Bryant, DCLS | <input type="checkbox"/> Phil Poston, DCLS |
| <input type="checkbox"/> Bonny Bukaveckas, VCU | <input type="checkbox"/> Nicole Safina, CHKD |
| <input type="checkbox"/> Tahnee Causey, VCU | <input type="checkbox"/> Ramona Schaeffer, VDH |
| <input type="checkbox"/> Ning Chen, VCU | <input type="checkbox"/> Alice Schroeder, Parent |
| <input type="checkbox"/> Justin Crow, VCU | <input type="checkbox"/> Cliff Schroeder, Parent |
| <input type="checkbox"/> Yasser El-Gohary, VCU | <input type="checkbox"/> Heather Trammell, Parent |
| <input checked="" type="checkbox"/> Sarah H. Elsea, VCU | <input checked="" type="checkbox"/> Susan Ward, VHHA |
| <input type="checkbox"/> Vicki Hardy-Murrell, Parent | <input checked="" type="checkbox"/> Joel Schmidt, M.D., VCU |
| <input type="checkbox"/> Jane Juusola, VCU | <input type="checkbox"/> Cynthia Epstein, M.D., EVMS |
| <input type="checkbox"/> Rees L. Lee, M.D., NMCP | <input type="checkbox"/> John P. Osborn, M.D., FNA |
| <input type="checkbox"/> Deborah K. Froh, M.D., UVA | <input type="checkbox"/> Beth Harkness, RN, BSN, CNMC |

Guests: Brooke Blessing, Katie Langley, Tom York, Veronica Kirkland, Greg Scott

Recorders: Rafael Randolph and Jennifer Macdonald

1. Welcome: B. Wilson

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- a. Introductions: Completed
 - b. Minutes of 10/04/2011 Meeting: Approved as written.
 - c. Agenda: No changes
 - d. Membership
 - e. Travel Reimbursement Reminder (members only): Travel Reimbursement forms passed out.
2. Public Comments: B. Wilson
 - a. None
3. Update on SCID Recommendation: K. Moline
 - a. VaGAC recommendation forwarded to the Virginia Department of Health (VDH) Commissioner. The addition of SCID will also need to go through the regulatory process. A SCID nurse has been hired to assist in the implementation process. Kathy Moline will be going to Albany, NY to attend a New York Mid Atlantic Consortium (NYMAC) sponsored SCID practicum.
4. Cystic Fibrosis Screening Update: J. Macdonald
 - a. CF screening data were presented. Data represented statistics since inception of CF transmembrane conductance regulator (CFTR) mutation screening which started December 1, 2011. A marked increase in the number of carrier infants has been identified and the potential burden of this to CF centers was discussed.
5. New York Mid-Atlantic Consortium (NYMAC) for Genetic and Newborn Screening Services: Tom Hickey with Table Top Specimen Drill
 - a. Kathy Moline and Tom Hickey attended NYMAC-sponsored practicum in Trenton, NJ. Focus was on how states can help each other in an emergency. Discussion centered on how to handle states' multiple screening panels, screening methodologies and computer systems and how to structure help in an emergency. Future exercises may be planned.
6. Update on Genetic Advisory Committee Bylaws: K. Moline
 - a. Broader committee membership and functions are being reviewed. Governor did dissolve hemophilia advisory board in this legislative session and now that board may be brought into VaGAC.
7. Subcommittees and Group Reports
 - a. Newborn Screening Subcmt: W. Andrews
 - (1) Cystic Fibrosis/DNA Update
 - (2) Other Subcommittee Updates
 - (a) SCID recommendation was brought forth at last meeting and sent to Commission of Health. Workshop was planned but on hold now.
 - (b) Jennifer Macdonald, Tom Hickey, and Phil Poston attended National Newborn Screening Meeting in San Diego in November.
 - (c) CF DNA screening started December 1, 2011.
 - (d) Subcommittee today will focus on instrumentation changes and next steps in SCID implementation process.
 - b. Birth Defects Prevention Subcmt: K. Moline
 - (a) Meeting this afternoon to review VA Cares fact sheets.
 - (b) Added ACT sheets to VDH NBSP website.

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- (c) Status of folic acid distribution is that it is continuing. Specific data not available for this meeting.
- c. VDH Contractors Ad Hoc Work Group: K. Moline
 - (1) No update
- 8. Updates: Agencies and Organizations
 - a. VDH: Virginia Newborn Screening Program (VSNP): K. Moline
 - (1) Follow-up data for 2010 was presented. 99.5% of infants born in Virginia were screened and 9,000 abnormal values were followed-up on. Approximately 182 cases were diagnosed.
 - (2) Susan Ward from Virginia Hospital Association (VHA) commented that Virginia hospitals will start offering parents their infant's single blood spot to take home starting July 1, 2012. Offering this is mandatory for all Virginia hospitals. In March, VHA sent hospitals an informational package on how to implement, which recommended a consent process. Florida is the only other state that has legislated this type of action, but it is optional for their hospitals. Discussion ensued about how collection of this single blood spot could affect collection of the traditional NBS blood spot. It may be prudent for follow-up and DCLS staff to monitor statistics on number of unsatisfactory specimens during the time period surrounding initiation of this mandate.
 - b. VDH: Virginia Early Hearing Detection and Intervention Program (VEHDIP): R. Frierson
 - (1) No update.
 - c. VDH: Virginia Congenital Anomalies Reporting and Education System (VaCARES): R. Randolph
 - (1) 2011 data was presented on the 5 genetic anomalies reported most and then broken down by region:
 - 1) Cranio-facial anomalies – 199 cases reported
 - 2) Cleft lip/Cleft palate – 179 cases reported
 - 3) Microcephalus – 77 cases reported
 - 4) Tetralogy of fallot – 70 cases reported
 - 5) Hydrocephalus – 69 cases reported
 - (2) Individual center reports will be discussed at genetics subcommittee after this meeting.
 - d. VDH: Children with Special Health Care Needs Program (CSHCN), including Care Connection for Children (CCC) and Child Development Clinics (CDCs): S. Dallas
 - (1) Welcome to Sidnee Dallas, new program manager for CSHCN.
 - e. Division of Consolidated Laboratory Services: W. Andrews
 - (1) Happy Lab Week, the week of April 23rd.
 - (2) Dr. Jim Pearson retired in March. Dr. Tom York is new director.
 - (3) Dr. Phil Poston's position is now shared with other parts of the lab that utilizes mass spectrometry methodologies.
 - (4) Budget bill allowed for start of process to increase lab's capacity for a molecular lab. Construction process will take at least a year.

- f. March of Dimes: S. Long
 - (1) Currently working on the national Prematurity Campaign, a quality improvement process that lasts approximately 18 months and includes professional development in regards to promoting/increasing the number of deliveries of infants greater than 39+ weeks gestation. Nine Virginia hospitals applied for this grant including VCUHS, INOVA Fairfax, two Riverside Hospitals, 3 HCA hospitals in Richmond, and 1 Lynchburg hospital.
 - (2) Association of State and Territorial Health Officials (ASTHO) is spearheading the “8% challenge” that Dr. Remley has accepted. Goal is to reduce preterm births 8% by 2014.
 - (3) March of Dimes website has many CEU modules on genetics for many professionals.
- g. Virginia Department of Behavioral Health and Development Services (VDBHDS), Part C of IDEA: K. Durst
 - (1) No update.
- h. Virginia Deaf-Blind Project: V. Luther
 - (1) Donna Gillis is the new executive director. Currently working on annual report.
- i. New York-Mid-Atlantic Consortium (NYMAC) for Genetic and Newborn Screening Services: T. Hickey
 - (1) A senior scientist is going to Mayo clinic this month to be educated on the Region Collaborative Project tool founded by Piero Rinaldo. This is the last session that will be conducted.
- j. Virginia Association of Genetic Counselors: T. Causey
 - (1) No update.
- k. HRSA Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC): J. Monaco
 - (1) Did not attend January meeting. Next meeting is May 17-18. She has been formally moved to the follow-up and treatment committee that will specifically focus on formula issues.
- 9. Updates: Virginia Genetics and Metabolic Centers
 - a. Eastern Virginia Medical School (EVMS): G. Proud
 - (1) Dr. Samantha Shrier is a new clinician who starts on Sept 1, 2012.
 - (2) New Dean of Medicine started at EVMS.
 - (3) Chair of Pediatrics is currently open following the unexpected death of Dr. Lewis earlier this year.
 - b. University of Virginia (UVA): B. Wilson
 - (1) Dr. Jennifer Humberson has joined UVA as a medical geneticist, and has increased their clinic days to respond to increased demand. They are completing the first year of the Cystic Fibrosis Foundation grant for a pilot program related to family and professional education about the new “two tier” newborn screening for cystic fibrosis. UVA is hosting the state genetic counselors meeting in Charlottesville on May 14th.

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- c. Virginia Commonwealth University (VCU): L. Duncan
 - (1) Dr. Pandya is out of town and sends regards.
 - (2) Dr. Lewandowski is new Director of Genetics at VCUHS.
 - (3) Division is currently moving to electronic data system.
 - (4) Six genetic students are graduating this month.
- 10. New Business: B. Wilson
 - a. None
- 11. Next Meetings: B. Wilson
 - a. VaGAC Meeting
 - (1) Date: TBA
 - (2) Time: 10a.m. – noon
 - (3) Place: DCLS
 - b. VaGAC Steering Cmt Conference Call
 - (1) Date: TBA
 - (2) Time: TBA
 - (3) Place: TBA
- 12. Adjourn: B. Wilson
 - a. Meeting adjourned at 11:58a.m.